

Behind the Numbers...



The enclosed report, *Rhode Island Children with Special Health Care Needs: Findings From the 2001 National Survey of Children with Special Health Care Needs*, provides data on children with special health care needs in Rhode Island and issues relating to their health care. Rhode Island has made great strides in improving access to care for children with special needs; however, anecdotal reports from service providers working with these families indicate that families are still struggling with financial and social issues that are not captured by the data in the report. In order to quantify these challenges, the Office of Families Raising Children with Special Health Care Needs worked with community partners to design a survey for families. The survey specifically asked about the financial and social impacts of caring for a child with special health care needs and about gaps in Rhode Island's support system.

The Department of Health's Office of Families Raising Children with Special Health Care Needs, the Division of Family Health's Data and Evaluation Unit, and Family Voices of Rhode Island at the Rhode Island Parent Information Network conducted the family survey during the winter of 2005, working through primary and specialty care practices, through a direct mailing, and through the Family-To-Family Network list serve. A total of 242 families completed the survey.

A sample of the survey findings are shown on the other side of this page. The major issues include stresses that affect family life with spouses and other children, as well as personal impacts on health and employment. In order to respond to these issues, the Office of Families Raising Children with Special Health Care Needs is working to increase public awareness of the unique circumstances faced by these families. The Office is partnering with primary and specialty care practices to increase access to integrated, family-centered services throughout the special health care needs service delivery system.

For more information regarding the Office of Families Raising Children with Special Health Care Needs, contact Deborah Garneau at Deborah.Garneau@health.ri.gov or (401) 222-5929.

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- » Approximately half (51.2%) of the respondents were insured by RIte Care or Medicaid.
 - » More than two-thirds of the parents who responded (71.5%) were married and over half (53.7%) had more than a high school education.
 - » Among those parents who had other children (n=158), 82.3% reported that caring for their child with special needs affects the time they spend with their other children.
 - » Three out of five respondents (60.8%) agreed that caring for a child with special needs creates stress on important relationships (e.g., marriage, partner, etc.).
 - » More than four out of five respondents (80.6%) felt that caring for their child with special needs does not permit them to work as much as they would like.
 - » A similar proportion of respondents (82.6%) felt that caring for their child with special needs affects the kinds of activities they are able to do with their family.
 - » Approximately the same number of respondents (83.1%) felt overwhelmed a lot of the time, and 64.5% said that caring for their child has caused a decline in their physical or mental health.
 - » Over two-thirds (67.8%) of those surveyed reported that caring for their child with special needs has limited their support system (e.g., family, friends, etc.).